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A SPECIAL DIABETES SURVEILLANCE EVALUATIVE STUDY: THE NORTH CAROLINA REGISTER OF THE BLIND AND VISUALLY IMPAIRED

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ABSTRACT

North Carolina's State Center for Health and Environmental Statistics was awarded a three-year cooperative grant from the Centers for Disease Control to develop a surveillance system for diabetes-related mortality and morbidity. Statewide data sets were evaluated for their ability to monitor North Carolina's diabetic population with respect to their medical care and treatment, complications, and mortality, as well as to determine diabetes prevalence rates.

Persons with diabetes are at risk for developing circulatory, neurological, and renal system disorders. In their most debilitating forms, many of these disorders can be tracked using hospital discharge data. However, it is unlikely that the severe visual impairment or blindness that is many times associated with diabetes will ever result in a hospital stay, and therefore cannot be adequately monitored with hospital discharge data.

One of the only population-based registries of the blind and visually impaired in the United States is maintained by North Carolina's Division of Blind Services. This registry includes information regarding the cause of visual impairment or blindness, and therefore its usefulness in tracking cases caused by diabetes was assessed.

An evaluation of the North Carolina Register for the Blind and Visually Impaired reveals that while the data set has enormous possibilities for statewide surveillance of diabetes-related visual disability, it is fraught with many difficulties. Due to its primary evolution as a tool for service delivery, much of the information of foremost interest for monitoring purposes is missing or unknown. For all practical purposes, there is no quality control with respect to etiology or demographic data, and the overall level of compliance is unknown.

However, with improvements in quality control and more vigorous enforcement of the reporting mandate, the Register could be an effective monitoring tool for diabetes-related blindness. With these improvements, its value could go far beyond its utility for statewide planning. The North Carolina Register for the Blind and Visually Impaired has the potential to make a real contribution nationally; it could become virtually the only system in the country with reliable statewide information on diabetes-related blindness and visual impairment.